Three-year follow-up results of a residential community reintegration program for patients with chronic acquired brain injury

BRIEF REPORT

Three-Year Follow-Up Results of a Residential Community Reintegration Program for Patients With Chronic Acquired Brain Injury

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ABSTRACT. Geurtsen GJ, van Heugten CM, Martina JD, Rietveld AC, Meijer R, Geurts AC. Three-year follow-up results of a residential community reintegration program for patients with chronic acquired brain injury. Arch Phys Med Rehabil 2012;93:908-11.

Objective: To evaluate outcomes of a residential community reintegration program 3 years after treatment on independent living, societal participation, emotional well-being, and quality of life in patients with chronic acquired brain injury and psychosocial problems hampering societal participation.

Design: A follow-up assessment 3 years after treatment was compared with the 1-year follow-up assessment in a prospective cohort study.

Setting: A tertiary rehabilitation center for acquired brain injury.

Participants: Of the 67 patients assessed at the 1-year follow-up, 63 subjects (94%; 42 men; mean age at admission to treatment 24.7y; mean time postonset 5.1y) were available at the 3-year follow-up and taken into account in the analyses.

Intervention: A structured residential treatment program directed at improving independence in domestic life, work, leisure time, and social interactions.

Main Outcome Measures: Community Integration Questionnaire, Employability Rating Scale, living situation, school, work situation, work hours, Center for Epidemiological Studies-Depression scale, and the World Health Organization Quality of Life Scale Abbreviated (5 scales).

Results: There were no significant differences for any of the outcome measures between the 1-year and 3-year follow-up assessment.

Conclusions: These results indicate that the established significant and clinically relevant improvements after a residential community reintegration program remain stable in the long term.

Key Words: Brain injuries, chronic; Employment; Quality of life; Rehabilitation; Residential treatment; Treatment outcome.

ACQUIRED BRAIN INJURY is a significant health problem. Specifically, the functional consequences of moderate and severe acquired brain injury can have a considerable impact on the quality of life (QOL) of the patients as well as their families. The direct consequences of brain injury are often complicated by secondary, mostly psychosocial problems.[1] The complexity of these psychosocial problems may require a comprehensive neuropsychologic rehabilitation approach in the long term. Such approaches can be divided into neurobehavioral programs, residential community reintegration programs, and holistic day-treatment programs.[2] In a recent systematic review,[3] it was shown that these comprehensive rehabilitation programs lead to a reduction in psychosocial problems as well. However, the evidence is still limited due to methodologic shortcomings of the available studies, 1 of which is no or a relatively short follow-up.

Since the aforementioned systematic review was conducted, only 1 retrospective study with a 1-year follow-up appeared comparing 489 completers with 114 noncompleters of home-based and community-based postacute rehabilitation.[4] This study showed significant group differences for the Mayo-Portland Adaptability Index at discharge and at the 1-year follow-up. However, there was a high loss to follow-up. At 1 year, data of merely 23% of the completers and 18% of the noncompleters were available.

Recently, we published a prospective study[5] concerning a residential community reintegration program administered to 70 patients with chronic acquired brain injury and severe psychosocial problems hampering societal participation. This so-called Brain Integration Program (BIP) led to significant improvements in QOL, emotional well-being, work situation, and independent living that were maintained at the 1-year

List of Abbreviations

BIP	Brain Integration Program
CES-D	Center for Epidemiological Studies-Depression Scale
CIQ	Community Integration Questionnaire
ERS	Employability Rating Scale
GCS	Glasgow Coma Scale
QOL	quality of Life
TBI	traumatic brain injury
WHOQOL-BREF	World Health Organization Quality of Life Scale Abbreviated

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Supported by the Johanna Child Fund and BIO Child Rehabilitation Fund (grant no. 2003/0120-009).

No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit on the authors or on any organization with which the authors are associated.

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In-press corrected proof published online on Mar 22, 2012, at www.archives-pmr.org.

0003-9993/12/9305-01036$36.00/0
doi:10.1016/j.apmr.2011.12.008

follow-up in 67 (96%) of the patients. In addition, the cost-effectiveness of the BIP was determined.[6] It was concluded that the costs of the residential program can be recovered after 8 years in this relatively young population (mean age, 30y), provided that there is a stable psychosocial situation in the years after treatment. Against this background, the present study aimed to compare the living situation, societal participation, and emotional well-being 3 years after discharge from the BIP, with the previously published effects at the 1-year follow-up.[5] We expected to find a stable situation (ie, no significant differences between the 1- and 3-year follow-up).

METHODS

Participants

All patients who had been included in the primary study between August 2003 and February 2007,[5] and who still participated at the 1-year follow-up, were included (N=67). Initial inclusion criteria were: (1) having sustained acquired brain injury (either trauma, stroke, tumor, encephalitis, or hypoxia) at least 6 months ago, proven by computed tomography or magnetic resonance imaging; (2) having problems in social functioning, emotional control, and work integration leading to a Global Assessment of Functioning Scale score[7] less than 65; and (3) being 18 years or older. Exclusion criteria were: (1) suitability for regular outpatient cognitive rehabilitation programs; (2) severe disruptive behavior posing danger to other patients or staff; (3) complete lack of problem awareness leading to lack of willingness to change; (4) severe memory problems leading to absent or severely limited ability to store new information; and (5) severe drug addiction or, in case of mild drug addiction, unwillingness to stop drug abuse. All patients gave written informed consent according to the Declaration of Helsinki.[8] The study was approved by the regional medical ethics committee.

Intervention

The BIP is a residential community reintegration program, which took place in a tertiary rehabilitation center for acquired brain injury in the Netherlands, and was administered by a multidisciplinary team. The overall aim of the treatment program was to restore the individual balance between the demands of living independently, societal participation, and emotional well-being, taking into account each patient's capacities and limitations. For every pillar of the program, a treatment module was developed: (1) the independent living module, (2) the vocational module, and (3) the social-emotional module. The content of these modules has been extensively described in previous publications.[5,9] The treatment was offered on an individual basis for 90% of the time. After discharge from the program, no follow-up support was given.

Design

A prospective cohort study was conducted. Outcome assessment 3 years after cessation of the program was compared with the outcome 1 year after treatment.[5]

Outcome Measures

For societal participation 2 primary outcome measures were used.

Community Integration Questionnaire.[10] The Community Integration Questionnaire (CIQ) is a 15-item self-report questionnaire consisting of 3 subscales (Home Integration, Social Integration, and Productivity). The total score is used for evaluation and ranges from 0 to 29. A higher score represents a higher level of integration.

Employability Rating Scale.[11] The Employability Rating Scale (ERS) is a 1-item scale with 10 mutually exclusive categories describing the level of employability (paid, supported, sheltered, etc). The score ranges from 1 to 10. A higher score indicates a higher level of employability.

The following measures were used as secondary outcomes.

Living situation. The actual living situation was categorized into living independently, or not living independently.[5]

School situation. This dichotomous measure indicates whether patients are attending school.

Work situation. This dichotomous measure reflects whether patients have a paid job.

Work hours per week. This rates the amount of hours per week the patient is working.

For the domains of emotional well-being and QOL, the following secondary outcome measures were used:

Center for Epidemiological Studies-Depression Scale.[12] Emotional well-being was assessed using the 20-item self-report Center for Epidemiological Studies-Depression Scale (CES-D). The score ranges from 0 to 60 with higher scores representing higher levels of depression. Epidemiologic studies found a cutoff score $\geq$16 for being at risk of depressive symptoms.[13]

World Health Organization Quality of Life Scale Abbreviated.[14] The World Health Organization Quality of Life Scale Abbreviated (WHOQOL-BREF) is a 26-item self-report questionnaire, containing 2 items for overall QOL and general health that are combined to 1 overall score. The other 24 items are categorized into 4 domain scores: physical capacity, psychological well-being, social relationships, and environment. The overall score and the 4 domain scores were used in the analyses. The scores range from 4 to 20 with higher scores indicating higher QOL.

Procedure

A letter explaining the purpose of the study was sent to the patients by mail. The CIQ, CES-D, WHOQOL-BREF, and a questionnaire for living situation, school situation, work situation, and work hours per week were included. The patients were requested to fill in the questionnaires at home and return them by mail. The ERS was scored by an independent test assistant based on the replies regarding work situation. A reminder letter was sent to those who did not respond within 3 weeks. In addition, a telephone call was made by an independent test assistant after 5 to 6 weeks to explain the relevance of the study and motivate subjects to participate.

Statistical Analyses

Paired *t* tests were conducted for all nondichotomous outcomes (CIQ, ERS, work hours per week, CES-D, and 5 WHOQOL-BREF subscales) to determine whether significant changes had occurred between the 1-year and 3-year follow-up. To control for interaction between time and patients, Tukey tests of additivity were carried out.[15] This is one of the few tests used in randomized block designs and in reliability analysis to assess whether there is interaction between blocks/subjects and the within-subject factor (randomized block design) or between the rated objects and the raters. A significant F ratio would indicate differential effects among patients, possibly yielding nonsignificant overall *t* test results. The dichotomous outcomes (living situation, school situation, and work situation) were analyzed with McNemar tests. Furthermore, the effect sizes were calculated using partial eta squared values.

The partial eta squared value was considered small when ranging from .05 to .10, moderate when between .10 and .20, and large when greater than .20.[16] Alpha was set at .05 for statistical significance. All analyses were performed with SPSS17.[a]

RESULTS

Participants

Of the 67 patients who participated in the 1-year follow-up of the primary study, 63 subjects (94%) responded to our request to participate in this 3-year follow-up study. These patients had sustained a traumatic brain injury (TBI) (66.7%; n=42), stroke (9.5%; n=6), brain tumor (14.3%; n=9), encephalitis (6.3%; n=4), or hypoxia (3.2%; n=2). Forty-two patients were men (66.7%). Subjects had a mean age of 24.7±7.2 years at admission (range, 18–49). The mean time postbrain injury-start treatment was 5.1±5.3 years (range, 0.5–26.3). Of the patients with TBI, 71.4% had sustained a severe injury (lowest initial Glasgow Coma Scale [GCS] 3–8) and 28.6% had a mild injury (lowest initial GCS 13–15); however, patients always had concomitant computed tomography or magnetic resonance imaging abnormalities, indicating that no patient merely suffered from cerebral concussion. The patient characteristics are shown in table 1. Two patients refused to cooperate and 2 patients could not be located.

Outcomes

In table 2, the means and SDs of the nondichotomous outcomes at the 1-year and 3-year follow-up are displayed for the 63 patients. Employability, community integration, work hours, emotional well-being, and QOL all showed small but insignificant improvements. The *t* tests did not yield a significant difference for any outcome measure (see table 2). Tukey tests showed no significant values either, indicating no interactions between time and patients. The effect sizes are negligible showing no significant effects as well (partial η^2=.00–.04) (see table 2). In table 3, the dichotomous outcomes at the 1-year and 3-year follow-up are displayed. The number of patients working slightly increased and the number of patients living independently slightly decreased; however, the 3 dichotomous outcomes (work situation, school situation, and living situation) were stable in time (P=.307, P=.588, P=.202, respectively).

DISCUSSION

The purpose of this study was to examine the consolidation of the beneficial effects of a residential community reintegration program in patients with chronic acquired brain injury who had psychosocial problems hampering community reintegration. To this aim, a 3-year follow-up assessment was compared with the previously published 1-year follow-up outcome.[5] In view of the societal aims and the high costs of residential community reintegration programs, long-term follow-up data on societal participation are important to prove their cost-effectiveness. Unfortunately, the available studies in the literature have implemented no follow-up or a follow-up period of maximally 1 year.[3] To our knowledge this is the first prospective cohort study on residential community reintegration reporting a follow-up of more than 1 year. A comparison with earlier studies is therefore not possible. The observed maintenance of treatment effects at the 3-year follow-up in an available sample of 94% of the patients in the 1-year follow-up confirms the long-term (cost-)effectiveness of the BIP as reported in previous publications.[5,6] Consolidation of beneficial effects was found in the domains of independent living, societal participation, emotional well-being, and QOL, as can be seen by comparing the results with the results from the original treatment study.[5] For independent living, 25.4% was living independently before treatment which increased to 65.7% at the 1-year follow-up. In this study at the 3-year follow-up, this still was 58.7%. The CIQ score (13.0 before treatment and 16.8 at follow-up) showed a further increase to 17.9 at the 3-year follow-up. The number of patients working showed a further increase as well (17.9% before treatment; 53.7% at follow-up) to 65.1% at the 3-year follow-up. The amount of work hours increased (14.3 before treatment; 18.8 at follow-up) to 19.2 at the 3-year follow-up. The level of emotional well-being slightly increased (15.5 before treatment; 11.5 at follow-up) to 11.4 at the 3-year follow-up; a lower score on the CES-D

Table 1: Demographic and Clinical Characteristics of the Patients

Characteristic	Values	Range
Age at admission (y)	24.7±7.2	18–49
Time since onset (y)	5.1±5.3	0.5–26.3
GCS score TBI patients (lowest GCS within 24h: n=14)	7.8±4.7	3–15
Coma duration* (d)	21.8±30	.50–135
Work hours (only working patients)	18.7±11.2	2–40
Living independently	42 (66.7)	
School	14 (22.2)	
Patients at work	33 (52.4)	

NOTE. N=63. Values are mean ± SD or n (%).
*Only TBI patients.

Table 2: Means, SDs and Partial η^2 Values for Outcome Measures

Outcome Measure	1-y Follow-Up	3-y Follow-Up	*t* Test (*P*)	Tukey Test (*P*)	Partial η^2
ERS	5.03±2.26	5.29±2.41	.33	.53	.02
CIQ	16.70±4.29	17.38±4.35	.21	.90	.03
CES-D	11.48±8.92	11.37±9.34	.92	.67	.00
WHOQOL overall	14.23±2.97	14.85±2.77	.15	.57	.03
WHOQOL physical	14.73±2.81	14.77±2.81	.90	.99	.02
WHOQOL psychological	14.02±2.53	14.58±2.83	.11	.31	.04
WHOQOL social	14.21±3.76	14.58±3.83	.29	.85	.02
WHOQOL environment	15.16±3.40	15.80±2.83	.24	.16	.02
Work hours (only working patients)	18.17±10.20	19.15±9.88	.45	.80	.02

NOTE. N=63.
Abbreviation: WHOQOL, World Health Organization Quality of Life.

Table 3: Patients Living Independently, Attending School, or Work

Outcome Measure	1-y Follow-Up	3-y Follow-Up
Living independently	42 (66.7)	37 (58.7)
School	14 (22.2)	14 (22.2)
Work	33 (52.4)	41 (65.1)

NOTE. Values are n (%). N=63.

indicates a higher level of well-being. Hence, most outcome measures even showed slight further improvements, although not significant. The achieved good balance between school, work, and domestic responsibilities at the end of the program remained present as we expected. Patients appeared to be aware of their limitations and of the necessity to adjust daily activities to their individual abilities and were still able to keep this balance 3 years after treatment.

In this 3-year follow-up study, 4 patients were lost compared with the 1-year follow-up, of which 2 refused cooperation and 2 could not be located. This dropout number is small given the results of other studies reporting a loss to follow-up of approximately 80% after 1 year[4] and 3 years.[17] This high level of adherence limits the chance of selection bias. Given the fact that the break-even point for cost-effectiveness of the BIP is reached 8 years after discharge from the program,[6] a prolonged follow-up of the patients of at least another 5 years should be performed.

Study Limitations

The interpretation of the finding of small and nonsignificant differences indicating no change should be done with caution. The power to detect small changes can be seen as a limitation for this type of study. However, considering the presence of significant changes after treatment and the low to large effect sizes in the same patients[5] the power seems to be strong enough to detect change.

CONCLUSIONS

The results of this study indicate that the established significant and clinically relevant improvements after a residential community reintegration program remain stable in the long term.

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